

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

*serving all dystonia-affected persons
d'asservant toutes personnes atteintes de dystonie*



Dystonia Canada Report

A Newsletter from the
Dystonia Medical Research
Foundation Canada

2018 Jackson Mooney Patient
Grant Recipient:

Sarah Anderson

Full story on page 6



Fall 2018

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PAIN – The Four Components**
With Dr. Gordon Ko, MD

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2018 RENEWAL NOTICE!

Support DMRF Canada with a minimum
donation of \$40 annually and you will
continue to receive the latest news and
information about dystonia. Renew today
and you will receive:

- Two issues of the Dystonia Canada Report mailed to you each year;
- Six issues of the Moving Forward E-newsletter delivered to your inbox;
- Ongoing special notices of events and activities in your community;
- A tax receipt for your gift.

Dystonia Medical Research Foundation Canada

The Dystonia Medical Research Foundation (DMRF) Canada is a registered non-profit Canadian charity founded in 1976 by Samuel and Frances Belzberg of Vancouver, British Columbia. DMRF Canada funds medical research toward a cure, promotes awareness and education, and supports the well-being of affected individuals and families. We work in partnership with the DMRF in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and with other like-minded research organizations to fund excellent dystonia research in Canada.

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Foundation Update

Dear Friends,

The mission of the Dystonia Medical Research Foundation (DMRF) Canada is simple: **To fund research that leads to treatments and ultimately a cure, and to provide information and support for all who are affected by dystonia.**

Thanks to the support of our many generous donors like you, DMRF Canada has been able to fund research that is generating potential new treatments and leading us toward a cure, provide accurate information for patients and loved ones, and offer programs to improve the daily lives of those living with dystonia.

As a generous supporter to the dystonia community, we wanted to remind you that your donations continue to make an important impact within the

dystonia community. Thank you for your contributions. With your support, we know we will be able to make significant strides in finding a cure for dystonia.

Sincerely,



Stefanie Ince
Executive Director,
DMRF Canada
stefanieince@dystoniacanada.org



DMRF Canada is proud to partner with the Dystonia Medical Research Foundation (DMRF) to fund critical dystonia research. Scientific advancement in dystonia is possible due to support from the DMRF and the research environment the Foundation built over decades. Investment in basic research has led to sophisticated genetic studies and unprecedented drug discovery efforts.



The 2017 Annual Report is Now Available.

Visit: <https://dystoniacanada.org/2017annualreport>

We've Moved!

Canadian donations should be sent to:
Dystonia Medical Research Foundation Canada
550 St. Clair Ave West, Suite 209, Toronto ON, M6C 1A5
www.dystoniacanada.org/donate

It is the editorial policy to report on developments regarding all types of dystonia but not to endorse any of the drugs or treatments discussed. DMRF Canada encourages you to consult with your physician about procedures mentioned herein.



Paralympic Hopeful Shelby Newkirk Joins Laps of Love Campaign

It's such an exciting time for Laps of Love. Please help me welcome Para-Swimmer, Paralympic hopeful for Tokyo 2020 and two-time Canadian world record holder, Shelby Newkirk. Shelby is a 22-year-old para-swimmer who was diagnosed with generalized dystonia eight years ago. She's making waves in the swimming world by shattering the S7 women's 50m backstroke and her own world record in the S7 100-metre backstroke—twice in one day at the Canadian Swimming Trials in Edmonton earlier this summer. Shelby reached out to Laps of Love this summer wishing to join the campaign with a shared goal to help build dystonia awareness.

I couldn't be happier to have such an enthusiastic addition to the team. Shelby and I have connected on a dystonia front as well as on our passion for swimming. **Shelby has contributed 1,608 laps, bringing our laps total to 5,500 laps! We have made it past the 50% mark!!** Thanks Shelby! We are rooting for you! See you in the pool, Sumbul

Visit <https://www.dystoniacanada.org/lapsoflove> and help support Shelby and Sumbul reach their fundraising goal and support the important Laps of Love campaign.

In Tribute

DMRF Canada extends our condolences and gratefully acknowledges the generous gifts received in memory of the following.

Barbara Fagrie

Lynn Frederiks

Peter Klassen

Harry Lovering

Alice Joyce Low

Hazel McAdam

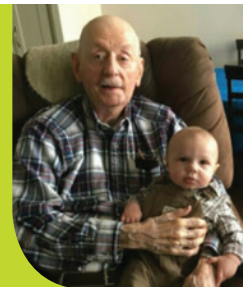
Julie Mintz

Stevie Schwartzberg

Ethel Waines-Main

Peter Naylor

Harry Lovering, Hamilton Support Group Leader



DMRF Canada wishes to express our deep sadness at the loss of Harry Lovering, who died peacefully surrounded by his family. The Hamilton Group is so very grateful that Harry was able to put the group together, allowing members from the Hamilton community to come together as dystonia patients without driving to Toronto. Harry helped to put together the very first Hamilton 'Walk' n' Wheel' event in 1996. Harry passed away at St. Joseph's Hospital in Hamilton, where he was born in 1932. On behalf of the many members of the Hamilton Support Group who benefitted from Harry's leadership, our deepest sympathies to Harry's family for this loss.

Sharing Our Stories

One of the ways for us to combat anxiety and isolation is to come together as a community. We are proud to partner with dystonia bloggers that are living with dystonia and are a voice for the community. For a list of some of the dystonia bloggers we love, please visit: www.dystoniacanada.org/bloggers. If you have recommendations or read about other dystonia patients working hard to 'defy' their own dystonia, please let us know! Email info@dystoniacanada.org. Read our dystonia patient stories at: www.dystoniacanada.org/patient-stories



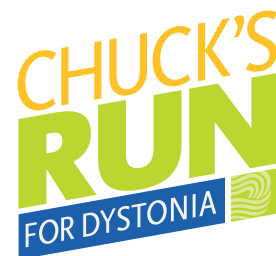


WALKING, RUNNING, WHEELING, WORKING TOWARDS A CURE

DMRF Canada is grateful for the efforts of all volunteers, participants, sponsors, supporters and donors, who work to improve dystonia awareness, raise funds for medical research, and come together to provide a safe and caring community for patients. This year's Freedom to Walk and Scotiabank Charity Challenge Events have **raised over \$80,000 for dystonia research**. Thank you for your support.

Chuck's Run, Walk, and Wheel for Dystonia

It was another fabulous event, with **over 150 walkers, runners and wheelers, plus over 150 volunteers, family and friends**. Thank you for coming out every year, to show others about the power of our community.



“My experience with Chuck's Run has been uplifting, and rewarding, and has erased the version of myself who viewed dystonia as a solitary burden that only I could understand. I've learned that events like Chuck's Run aren't about lamenting over challenges, or comparing battle scars, or wishing that life were somehow different. They are about family, and community, and celebration.

— John Fraser, Chuck's Run fundraiser and local area contact. For John's complete story on his Chuck's Run experience, visit: www.dystoniacanada.org/johnsstory

Our thanks to **Merz Pharma Canada Ltd.** our Platinum sponsor, and **Ipsen Biopharmaceuticals Canada Inc.** for their very generous support



Dystonia Support Group of Sudbury & District Walk-and-Wheel 2018



What an amazing Dystonia Walk-and-Wheel we had! Not only did we have a beautiful day, but 28 wonderful people showed up to raise over \$20,000 for dystonia research and support programs. This year, a milestone was reached when Dwayne Backer brought in \$11,818, bringing the total amount that he has raised over the last 18 years to over \$100,000. In this time frame Dwayne raised \$103,308 for dystonia medical research.

The top prize winners for the most pledges obtained were:

1) Dwayne Backer
2) Richard & Mary Guy

3) Coco Lariviere and
4) Lauraine Blais.

These prizes were donated by DMRF Canada. Congratulations to all of you! A very special thank you to Linda Thompson for once again organizing the BBQ. Food donations came from Linda Thompson, Chris Y.I.G., Tim Horton's and our dystonia fund. Thank you to Harry Thompson and his son, Kyle, for the delivery and use of their BBQ. Thanks to our chefs, Linda Thompson and Denise St. Georges. Door prizes were donated by Barrydowne Paint & Wallpaper, BBT Machining Inc., Maureen Clement, Rico Johnston, M&M Meats, Querney's Office Plus, The Rainville Clan, Scotiabank and Topper's Pizza.

Thank you to all the donors for your generosity.

Thank you to our experienced desk crew of Brenda Morris, Lise Depatie and Sue Leroux for setting things up and keeping track of the walkers and the money that they brought in. Everyone was so helpful it made set up and take down a breeze. **A very big thank you to everyone who sponsored our walkers and everyone who helped in making the walk such a success.**

Gratefully yours, Mary Guy, Support Group Leader Sudbury and District

Hamilton Walk and Wheel for Dystonia – 2018

This year's Hamilton Walk, and Wheel for Dystonia went very well, with a new face taking the lead with event planning! Ashley, our Lead Volunteer, and her wonderful team of volunteers did a great job. We had 81 participants with many familiar faces and supporting us. Thank you for another wonderful event. Together we raised over \$4,000 for dystonia research and support programs!

Funds Raised from Scotiabank Charity Challenge in Montreal and Vancouver Benefitting Dystonia Research and Support

"I joined this walk because I wanted to share and spread awareness of dystonia. It took me 20 years (after I was diagnosed), to actually get in contact with someone who had the same diagnosis than me. These 5 KMs mean more than just being able to walk again. To me it means I can be there for someone who needs the support of someone who understands exactly what they are going through. Let's be strong together!"

—Jessica O, Vancouver Walk Leader



A Community Strong: *Support for Patients*

You are not alone. There are dozens of local support groups, area contacts, and individuals who have dystonia who are waiting to hear from you. Visit: www.dystoniacanada.org/connect.

Webinar for Parents of Children Who Have Dystonia

When a child is diagnosed with dystonia, parents may not know where to turn. The process of diagnosis and coping with symptoms can be overwhelming. Join Stefanie Ince, Executive Director, DMRF Canada, and Inge A. Meijer MD, PhD, FRCPC for a special webinar presentation on Thursday, November 15, 2018 at 7:00 PM EST.

To RSVP for this session, please email info@dystoniacanada.org

If you do have a specific question please include it in this email request.

Funding critical Dystonia research here in Canada:

DMRF Canada Funds Dystonia Research in Partnership with Banting Research Foundation



We are thrilled to announce that together with the Banting Research Foundation, DMRF Canada is proud to support Nomazulu Dlamini, MD PhD. Neurology, from The Hospital for Sick Children (SickKids).

Dr. Dlamini's research project, entitled: *Neural network reorganization and maladaptive plasticity in dystonia post childhood basal ganglia stroke: a developmental model for the investigation of the neurobiological substrate of dystonia*, was selected to be the DMRF Canada supported Discovery Award grant for 2018. The Banting Research Foundation Discovery Award supported by DMRF Canada is a one-year grant of \$25,000.

Dr. Dlamini's research will investigate how disturbances within the basal ganglia are implicated as a common pathway of dystonia. In children with basal ganglia stroke post-stroke, dystonia is one of the commonest movement disorders of childhood, providing a unique window to examine the network differences between children with and without post-stroke dystonia.

Dr. Dlamini explains; "The knowledge obtained through this research will improve understanding of 'why dystonia occurs, when it occurs, and in whom it occurs', potentially providing paradigm shifting opportunities for the development of future mechanism and individual targeted therapies to impact the quality of life of children, adults, and their communities".

The Discovery Award Grant, supported by DMRF Canada, was awarded through the grant program of the Banting Research Foundation with input from the DMRF Medical and Scientific Advisory Committee. Jan Teller, Chief Scientific Officer at DMRF said of Dlamini's research; "this is a very original application from an exceptionally well-trained faculty. The proposal is highly relevant to dystonia and DMRF is happy to support it in partnership with the Banting Research Foundation."

Congratulations to Dr. Dlamini and her team at SickKids. We look forward to hearing more on this exciting research in the months to come.

DMRF Canada Invests More Money into Dystonia Research

DMRF Canada Launches Clinical and Research Fellowship:

For the second year, DMRF Canada is funding a Clinical Fellowship for Movement Disorders with a specialty in dystonia. But this time, we're doubling our investment so that this is a two-year commitment. This two year Clinical and Research Fellowship will launch later this fall – encouraging new young investigators into the field. Visit: www.dystoniacanada.org/research for more information.

NEW for 2018: DMRF Canada is proud and excited to announce the first ever Pilot Project Program for Dystonia Research in Canada. The objective of this research is to support an investigator whose research focuses on better clinical treatments for patients. This grant will launch in November 2018.

If you want to support critical dystonia research, please turn to the back cover and make your donation today!